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# Determining Capacity to Make Medical Treatment Decisions: Problems Implementing The Mental Capacity Act 2005 Emma Cave\*

#### Abstract

The Mental Capacity Act 2005 sets out a ground-breaking statutory framework to empower and protect vulnerable people who are incapable of making their own decisions. The Act incorporates empowering and safeguarding measures, but the balance between the two is precarious. The Act was scrutinised in a House of Lords Select Committee report in 2014, which concluded that, whilst the principles of the Act are well supported, a raft of measures is urgently needed to improve poor understanding and implementation of the empowering ethos of the Act. Some people who are capable of supported decision-making are instead subjected to the decisions of others. The Act is one of a number of laws governing decisions to consent to and refuse medical treatment. As problematic as the failure to comply with the terms of the Act is the exclusion of some groups from its remit. Implementation of the Act, and compliance of our laws with human rights (and the UN Convention on the Rights of Persons with Disabilities in particular), is dependent upon a broader commitment to empowerment. This article considers how this might be achieved.

#### I. INTRODUCTION

In England and Wales, the Mental Capacity Act 2005 (MCA) and accompanying Code of Practice set out a test for mental incapacity and safeguards for the treatment of adults and 16/17 year olds who are found to lack capacity. The Act applies to health, welfare and financial decisions, but in this paper, I will focus on medical treatment decisions. The MCA attempts to balance safeguarding of vulnerable people and their empowerment to make decisions for themselves. Not all agree that this is a worthwhile pursuit. Conly<sup>1</sup>, for example, argues that legal capacity is a flawed mechanism for determining who should and should not be allowed to make harmful choices. It is incapable, she argues of differentiating between rational and irrational choices.<sup>2</sup> She suggests that hard paternalism may be justified to protect people from irrational decisions. The MCA, however, takes a different stance, aiming to protect the right of those capable of making the decision in question to do so and reserving paternalistic measures for those who cannot.

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With thanks to Professor Shaun Pattinson for comments on an earlier draft. All remaining errors are my own. <sup>1</sup> S. Conly, *Against Autonomy: Justifying Coercive Paternalism* (Cambridge, 2012).

<sup>&</sup>lt;sup>2</sup> Conly, ibid, 5: '[O]nce again this proves to be less than an entirely clear division – surely some of us who are generally competent have, at times, thought in just those ways that are typical of the incompetent'.

Section 1 sets out the core principles at the heart of the legislation: the right to make decisions for oneself is protected by an assumption of capacity; a right to support; and a right to make decisions that others consider to be unwise. The assumption of capacity<sup>3</sup> is rebuttable only where the individual has an impairment of the mind or brain and is unable to understand, retain, use or communicate the information needed to make the particular decision.<sup>4</sup> Where the assumption is rebutted, the 'best interest test'<sup>5</sup> applies in which case others make a decision on the individual's behalf, by the least restrictive option, taking into consideration the person's past and present wishes, feelings, values and beliefs.<sup>6</sup>

In March 2014, a review of the Act by a House of Lords Select Committee<sup>7</sup> reported that the Act's core principles are well supported, but the Act is not working as intended.<sup>8</sup> There are, the Committee found, misperceptions regarding the application of the five core principles of the Act.<sup>9</sup> The sharp legal distinction between capacity and incapacity defies the reality that there is often a grey area between them.<sup>10</sup> There is evidence of a lack of commitment to the empowerment and enablement<sup>11</sup> promised in the statute.

The Select Committee was not the first to point out the gap between theory and practice. Contrary to the assumption of capacity in the MCA,<sup>12</sup> a 2012 study commissioned by the Policy Research Programme in the Department of Health showed that a significant number of decisions are made in the best interests of a patient without ever assessing mental capacity.<sup>13</sup> The Select Committee found evidence of confusion as to which decisions require a formal assessment,<sup>14</sup> particularly where treatment is consensual.<sup>15</sup> Where assessments *are* made, they are sometimes of poor quality, or are not recorded.<sup>16</sup> Many decisions seem to be predicated on the fact that the patient is at risk of harm. Conversely, the Select Committee heard evidence that the assumption of mental capacity can be used perversely – to justify non-assessment or inaction, leaving vulnerable people at risk.<sup>17</sup>

The 2012 study also demonstrated confusion surrounding the *application* of the test for mental capacity. The Act requires that the test is applied in relation to the particular decision or task, rather

<sup>&</sup>lt;sup>3</sup> Mental Capacity Act 2005, s 1(2).

<sup>&</sup>lt;sup>4</sup> Mental Capacity Act 2005, ss 2, 3.

<sup>&</sup>lt;sup>5</sup> Set out in Mental Capacity Act 2005, s 4.

<sup>&</sup>lt;sup>6</sup> Mental Capacity Act 2005, s 4(6).

<sup>&</sup>lt;sup>7</sup> Select Committee on the Mental Capacity Act 2005, *Mental Capacity Act 2005: Post-Legislative Scrutiny*, HL Paper 139, (March 2014).

<sup>&</sup>lt;sup>8</sup> Ibid, paras 2, 104.

<sup>&</sup>lt;sup>9</sup> Select Committee (n7), chapter 3.

<sup>&</sup>lt;sup>10</sup> M.I. Hall, 'Mental Capacity in the (Civil) Law: Capacity, Autonomy and Vulnerability' (2012) 58(1) *McGill Law Journal* 61.

<sup>&</sup>lt;sup>11</sup> Mental Capacity Act 2005, ss 1(3), 3(2), 4(4).

<sup>&</sup>lt;sup>12</sup> Mental Capacity Act 2005, s 1(2): 'A person must be assumed to have capacity unless it is established that he lacks capacity.'

<sup>&</sup>lt;sup>13</sup> V. Williams, G. Boyle, M. Jepson, P. Swift, T. Williamson, P. Heslop, *Making Best Interests Decisions: People and Processes* (Bristol, Bradford, 2012), 6: '1:10 best interests decisions did not follow an assessment that the person lacked capacity'.

<sup>&</sup>lt;sup>14</sup> Select Committee (n7), para 74.

<sup>&</sup>lt;sup>15</sup> Ibid, para 75.

<sup>&</sup>lt;sup>16</sup> Ibid, para 66.

<sup>&</sup>lt;sup>17</sup> Ibid, para 63.

than to the person, yet: <sup>18</sup> 'Around one quarter of the best interests decisions studied were made on the basis of a capacity assessment relating to history, diagnosis or disability, age, appearance or behaviour, or the fact that someone was making an unwise decision.' <sup>19</sup> One of the MCA principles is that 'A person is not to be treated as unable to make a decision merely because he makes an unwise decision', <sup>20</sup> but it is apparent that, in practice, it is sometimes difficult to distinguish an unwise decision from a lack of functional ability to make a decision.<sup>21</sup>

The Select Committee also reports poor compliance<sup>22</sup> with the MCA requirement that: 'A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.'<sup>23</sup> The Act focuses on both safeguarding and empowerment, but in practice the former dominates. Too often, capacity is not assumed; incapacity is not assessed; unwise decisions are seen as evidence of incapacity; and too little is done to support individuals to make a capax decision. Individuals who fall into the grey area between capacity and incapacity are too readily assigned to the latter group.

The Lords Select Committee made 39 recommendations addressing these and a range of other issues not covered in this article.<sup>24</sup> The Committee also made proposals for reform, some of which the Government intend to take forward.<sup>25</sup> The Committee's emphasis on the practical interpretation and implementation of the MCA is admirable. This article adds an appreciation of the broader scheme of laws relevant to medical treatment decisions and their impact on the MCA implementation agenda. The Select Committee's remit was restricted to an evaluation of the Mental Capacity Act. It did not consider the different rules that apply to those under 16 and to people with psychosocial disorders. These laws are increasingly controversial in light of modern interpretations of the UN Convention on the Rights of the Child (CRC), which moves towards a rights based approach centered on the evolving capacities of the child; and the UN Convention on the Rights of Persons with Disabilities (CRPD), which embodies a shift away from a social welfare response to disability, to a rights based approach. This article considers the interaction of the MCA with other laws governing medical treatment decisions. Philosophical and human rights developments point to flaws in the ability of the MCA to fulfil its original remit. Furthermore, the argument is put forward that the incoherent principles applicable in laws which, in practice, may overlap and interact, is a contributory factor in the failure to implement the facilitative ethos of the MCA. This article considers the implications and options in light of a political resistance to radically reform the capacity framework in England and Wales, arguing that it is becoming increasingly important to deliver upon and extend the promises made in the MCA.

<sup>&</sup>lt;sup>18</sup> V. Williams et al (n13), 7.

<sup>19</sup> Ibid.

<sup>&</sup>lt;sup>20</sup> Mental Capacity Act 2005, s. 1(4).

<sup>&</sup>lt;sup>21</sup> V. Williams et al (n13), 6.

<sup>&</sup>lt;sup>22</sup> Select Committee, (n7), para 5 and 107.

<sup>&</sup>lt;sup>23</sup> Mental Capacity Act 2005, s 1(3).

<sup>&</sup>lt;sup>24</sup> This article does not, for example, consider the controversial issues surrounding the Mental Capacity Act Deprivation of Liberty Safeguards, which came into effect on 1st April 2009 and provide for the lawful deprivation of liberty of those people who lack the capacity to consent to arrangements made in their best interests.

<sup>&</sup>lt;sup>25</sup> HM Government, Valuing Every Voice, Respecting Every Right: Making the Case for the Mental Capacity Act Cm 8884 (June 2014).

The article is in 3 sections. First it reviews the laws on capacity in relation to medical treatment and argues that the MCA does not address the issues it was designed to resolve. Not only, in practice, is the promise to support people to make their own decisions poorly implemented,<sup>26</sup> but there are groups of people whose decisions regarding medical treatment are vetoed by virtue of their status, despite their ability to make an autonomous decision. The second section contends that this is one of a number of factors that limit the proper implementation of the MCA. In the final section, the article considers ways forward.

# II IS THE LAW ON CAPACITY FIT FOR PURPOSE?

The MCA was a long time in the framing. The Law Commission's 1995 report on Mental Incapacity set out the problems the legislation sought to address:

It is widely recognised that, in this area, the law as it now stands is unsystematic and full of glaring gaps. It does not rest on clear or modern foundations of principle. It has failed to keep up with social and demographic changes. It has also failed to keep up with developments in our understanding of the rights and needs of those with mental disability.<sup>27</sup>

The result was liberal, progressive, rights based<sup>28</sup> and much praised, and there remains considerable support for its core principles. But rights have developed and social change continues apace. In the next section, the legislation is assessed against each of these pre-Mental Capacity Act criticisms in order to show that, whilst the Act might initially have resolved these issues to the satisfaction of many, the criticisms are once again applicable.

# A. <u>The law is unsystematic and full of glaring gaps.</u>

The first criticism of the pre-MCA law was that it was 'unsystematic and full of glaring gaps'. Seven years since the MCA came into force, there are a number of prominent gaps resulting in differential treatment of people capable of making an autonomous treatment decision. Gaps in the law *as applied* (that is, the failure to apply the Act's principles) have already been referred to. Whether gaps in the law *as written* are 'unsystematic' depends on whether the restricted remit of the Act is considered justifiable. This sub-section outlines the limited reach of the MCA. Subsequent subsections argue that certain status-based denials of capacity are becoming increasingly difficult to defend given developments in modern principle; the human rights implications; and the practical impact they may have on the implementation of the MCA.

One of the aims of the MCA is to limit paternalistic decision-making to those cases where a person lacks capacity (as defined in the Act). However, the public interest in protecting vulnerable groups from their own harmful decisions has resulted in a number of exceptions to the general principle. These exceptions are controversial where the patient is in fact capable of making an autonomous treatment decision, or when they are discriminatory in nature. The exceptions can be categorised into three groups.

<sup>&</sup>lt;sup>26</sup> Select Committee (n7), paras 2, 104.

<sup>&</sup>lt;sup>27</sup> Law Commission, *Mental Incapacity* (1995), para 1.1.

<sup>&</sup>lt;sup>28</sup> M. Donnelly, 'Best interests, Patient Participation and the Mental Capacity Act 2005' (2009) 17 *Medical Law Review* 1, 14.

Firstly, other tests for capacity may operate alongside the test set out in the statute. In 2012 it was confirmed that the statutory test for capacity is not exhaustive. The court's inherent jurisdiction to protect vulnerable people whose capacity is compromised by reason of coercion or undue influence, constraint or 'other disabling circumstances' was affirmed in *DL v A Local Authority and others*.<sup>29</sup> DL, it was held, had mental capacity under the Mental Capacity Act but not at common law. The case concerned decisions about residence and contact, but the same reasoning could apply to medical treatment decisions. The Court of Appeal was clear that the common law should sit harmoniously alongside the MCA test and should not be applied so as to subvert the will of parliament.<sup>30</sup> Nonetheless, to recognise that a person has capacity under the MCA only to remove it at common law has understandably proved controversial.<sup>31</sup>

A comparable situation arises in relation to medical treatment decisions made by minors aged 16/17. Much of the Act applies to those 16 and over, but the MCA Code of Practice recognises that whilst some 16/17 year olds might lack capacity due to an impairment of the mind or brain (so as to satisfy the test for incapacity in section 2), others will be 'unable to make the decision for some other reason' in which case they 'should be assessed under common law principles'.<sup>32</sup> For both 16/17 year olds and adults who are subject to undue influence, a decision that is recognised as capax under the MCA framework might nonetheless be viewed incapax at common law.

Secondly, there are situations where the capacity regime applies, but the link between capacity and authoritative decision-making is broken when certain conditions apply. The Mental Health Act 1983 (MHA) governs compulsory treatment of both young people and adults with mental disorder. As we shall see, a capax refusal might be overridden to protect third parties or, more controversially, the patient. Similarly, at common law, there are circumstances in which competent refusals of treatment by minors under the age of 18 can be overruled in their best interests.<sup>33</sup>

Thirdly, some people are excluded from the remit of the Act. In such cases, the fact that a patient would be recognised as having capacity under the MCA might nonetheless result in a finding of incapacity because a different test, with a higher threshold for capacity is applied. This is the case in relation to minors under the age of 16, who must demonstrate *Gillick* competence<sup>34</sup> if they are to give a valid consent to medical treatment. There is no requirement to facilitate capacity.<sup>35</sup> The test is

<sup>&</sup>lt;sup>29</sup> DL v A Local Authority and others [2012] EWCA Civ 253, [78]. Discussed in E. Cave, 'Goodbye Gillick? Identifying and Resolving Problems with the Concept of Child Competence' (2014) 34(1) Legal Studies 103, 120-121.

<sup>&</sup>lt;sup>30</sup> *DL* ibid, [48], citing Munby J in *Re PS (An Adult)* [2007] EWHC 623, [119].

<sup>&</sup>lt;sup>31</sup> B. Hewson, 'Neither Midwives Nor Rainmakers: Why DL is Wrong' (2013) *Public Law* 451; G.T. Laurie, J.K. Mason, 'Trust of Contract: How Far Does Contemporary Doctor / Patient Relationship Protect and Promote Autonomy?' in *Festschrift for Sheila McLean*, forthcoming, chapter 17.

<sup>&</sup>lt;sup>32</sup> Department for Constitutional Affairs, *Mental Capacity Act Code of Practice* (2007), para 12.13.

<sup>&</sup>lt;sup>33</sup> Re<sup>W</sup> (A Minor) (Medical Treatment: Court's Jurisdiction) [1993] Fam 64; An NHS Foundation Hospital v P [2014] EWHC 165.

<sup>&</sup>lt;sup>34</sup> *Gillick v West Norfolk and Wisbech Area Health Authority* [1986] AC 112.

<sup>&</sup>lt;sup>35</sup> E. Cave, 'Maximisation of a Minors' Capacity' (2011) 4 *Child and Family Law Quarterly*, 429. And see evidence of this in *F (Mother) v F (Father)* [2013] EWHC 2683 (Fam), discussed in E. Cave, 'Adolescent Refusal of MMR inoculation' (2014) 77(4) *Modern Law Review* 619.

vague and in some cases involving the refusal of life-sustaining treatment, the threshold applied has been considerably higher than that applied to adults.<sup>36</sup>

The MCA was intended to provide a 'single comprehensive piece of legislation making provisions for people who lack capacity'.<sup>37</sup> Hailed as a success when it was enacted, some of the exceptions that might once have been readily justified according to the prevalent charitable approach, must now be reconsidered in light of human rights developments. Where differential treatment is inconsistent with human rights then the pre-MCA criticism that the law was 'full of glaring gaps' might once again apply.

# B. <u>The law has failed to keep up with human rights developments and the needs of those with</u> <u>mental disability</u>

The Law Commission was critical of the failures of the pre-MCA law to 'keep up with human rights developments', which unsurprisingly have not ceased since the Act came into force. The emphasis in the MCA on individual autonomy rights was liberal and progressive. It accorded with judicial recognition of autonomy *interests*<sup>38</sup> and their evolution<sup>39</sup> into autonomy *rights*.<sup>40</sup> There is no mention of autonomy in the European Convention on Human Rights, but the Convention is a living document and the right has been acknowledged and applied by the European Court of Human Rights, as part of the suite of protections encompassed in the Article 8(1) right to a private and family life.<sup>41</sup> Compulsory medical treatment has potential to breach (amongst other rights) Article 8(1). Once this Article is 'engaged', the State bears the burden of demonstrating that breach falls within one of the exceptions in Article 8(2) and that it is in accordance with law and necessary in a democratic society. Article 8(2) might be invoked to protect vulnerable people from their own harmful decisions on the basis that they lack capacity or otherwise lack decision-making authority.<sup>42</sup>

This position accords with J.S. Mill's proviso to his oft-quoted harm principle:<sup>43</sup> 'It is, perhaps, hardly necessary to say that this doctrine is meant to apply only to human beings in the maturity of their faculties.'<sup>44</sup> But vulnerability is a social construct and its accepted definition is subject to change, as is the societal response to the identification of vulnerability. J.S. Mill stated:

<sup>&</sup>lt;sup>36</sup> *Re E (A Minor) (Wardship: Medical Treatment)* [1993] 1 FLR 386; *Re L (Medical Treatment: Gillick Competence)* [1998] 2 FLR 810.

<sup>&</sup>lt;sup>37</sup> Law Commission (n27).

<sup>&</sup>lt;sup>38</sup> Airedale NHS Trust v Bland [1993] 1 All ER 821 at 866.

<sup>&</sup>lt;sup>39</sup> Chester v Afshar [2004] UKHL 41, [92] per Lord Walker: 'the importance of personal autonomy has been more and more widely recognised.'

<sup>&</sup>lt;sup>40</sup> *Chester,* ibid, [87] per Lord Hope: 'The function of the law [on informed consent] is to protect the patient's right to choose.'

 <sup>&</sup>lt;sup>41</sup> Eg Pretty v UK (2002) 35 EHRR 1, [61]; *Ternovszky v Hungary* (Application no. 67545/09, Judgment of 10 December 2010, [22]. See also *KH and Others v Slovakia*, (Application no. 32881/04), Judgment of 28 April 2009; *Jehovah's Witnesses of Moscow and Others v Russia*, (Application no. 302/02), Judgment of 10 June 2010; *Schneiter v Switzerland* (Application no. 63063/00), Judgment of 31 March 2005; *X v Finland* (Application no. 34806/04), Judgment of 3 July 2012.
<sup>42</sup> See for example, *R (on the application of PS) v (1) Responsible Medical Officer (Dr G) (2) Second Opinion*

<sup>&</sup>lt;sup>42</sup> See for example, *R* (on the application of *PS*) v (1) Responsible Medical Officer (Dr G) (2) Second Opinion Appointed Doctor (Dr W) [2003] EWHC 2335 Admin, where compulsory treatment for mental disorder against the will of an adult with capacity was held to be justified under Article 8(2).

<sup>&</sup>lt;sup>43</sup> J.S. Mill, *On Liberty* (London, 1969), p. 72. '... the only purpose for which power can be rightfully exercised over any member of a civilised community, against his will, is to prevent harm to others.'

<sup>&</sup>lt;sup>44</sup> J.S. Mill ibid.

We are not speaking of children, or of young persons below the age which the law may fix as that of manhood or womanhood. Those who are still in a state to require being taken care of by others, must be protected against their own actions as well as against external injury. For the same reason, we may leave out of consideration those backward states of society in which the race itself may be considered as in its nonage.<sup>45</sup>

Aspects of Mill's proviso are inapplicable today. Similarly, developments in human rights lead us to question the position on vulnerability adopted in the framework of laws that apply to medical treatment decisions. This section focuses on two groups in particular - those with psychosocial disabilities and young people - and considers the claim that a denial of capacity flows from their status.

# Young people

Rebuttable presumptions of capacity apply to 16 and 17 year olds under both the Mental Capacity Act 2005 and the Family Law Reform Act 1969. However, the dual application of the Acts potentially enables the presumption to be rebutted in a wider set of circumstances than would apply to an adult under the MCA. It has been held at common law that section 8(3) of Family Law Reform Act 1969 preserves the inherent jurisdiction of the High Court to overrule a refusal of treatment which is contrary to the minor's interests (because treatment is needed to preserve life).<sup>46</sup>

The capacity test that applies to under 16 year olds requires that understanding is measured and tested, not facilitated and enabled.<sup>47</sup> A test set down by Lord Scarman in *Gillick v West Norfolk Area Health Authority*<sup>48</sup> recognises as competent, decisions made by those minors who have 'sufficient understanding and intelligence to enable him or her to understand fully what is proposed'.<sup>49</sup> Minors who fall into this bracket can give the legal authority for medical treatment provided it is in their best interests to do so. The threshold for competence to refuse (particularly life-sustaining) treatment, however, has been set so high as to be arguably impossible to achieve<sup>50</sup> or denied altogether.<sup>51</sup> The resulting lack of symmetry between the right to consent and the right to refuse treatment has been much maligned.<sup>52</sup> Hagger argues that greater weight should be attached to children's autonomy, by empowering minors as decision-makers. The best way to achieve this, she argues, is through a human rights framework.<sup>53</sup> The UK signed the UN Convention of the Rights of the Child in 1990, ratified it in 1991 and it came into force in 1992. Article 12 requires that children's views should be heard and given due weight. The 'evolving capacities approach' taken in Article 12<sup>54</sup>

<sup>&</sup>lt;sup>45</sup> J.S. Mill ibid, p. 73.

<sup>&</sup>lt;sup>46</sup> *Re W* (n33).

<sup>&</sup>lt;sup>47</sup> Discussed in E. Cave, (n29), 106-107.

<sup>&</sup>lt;sup>48</sup> Gillick v West Norfolk and Wisbech Area Health Authority [1986] AC 112.

<sup>&</sup>lt;sup>49</sup> Ibid, 253.

<sup>&</sup>lt;sup>50</sup> *Re E* (n36); *Re L* (n36).

<sup>&</sup>lt;sup>51</sup> Re R (A Minor) (Wardship: Consent to Medical Treatment) [1992] Fam 11.

<sup>&</sup>lt;sup>52</sup> Critics are summarised and analysed in S. Gilmore, J. Herring, "No' is the Hardest Word: Consent and Children's Autonomy' (2011) 23 *Child and Family Law Quarterly* 3, 4.

<sup>&</sup>lt;sup>53</sup> L. Hagger, *The Child as Vulnerable Patient: Protection and Empowerment* (Ashgate, 2009).

<sup>&</sup>lt;sup>54</sup> Article 12 '(1) States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child. (2) For this purpose, the child shall in particular be provided

arguably goes further than our current law in its commitment to hearing and heeding the views of the minor. There is evidence that some judges are starting to embrace a rights based approach,<sup>55</sup> but 20-year-old legal precedents that adopt a paternalistic stance<sup>56</sup> have yet to be challenged. Where minors are capable of making an autonomous decision (and clearly not all children are), the vague test for competence enables the threshold to vary according to the outcome of the decision. I have argued elsewhere that this has potential to breach the human rights of minors.<sup>57</sup>

# Psychosocial disability

Across the world, people with psychosocial disabilities suffer considerable human rights abuses.<sup>58</sup> Accounts of people left chained to their beds and subjected to forced treatment regimens are by no means confined to the history books. In Europe, controversial treatments such as 'mega-dosing' (giving doses beyond the recommendations), psychosurgery and sterilisation are particularly problematic when they are administered without consent. These are practices that may conflict with the European Convention on Human Rights prohibition of inhuman and degrading treatment (Article 3) and with rights to liberty (Article 5) and to a private and family life (Article 8 and also Article 6 of the Convention on Human Rights and Biomedicine).<sup>59</sup> There are widespread concerns about compulsion in the treatment of mental health conditions<sup>60</sup> but this section is confined to the potential inequality that flows from legal recognition that treatment can be imposed on individuals to protect them from harm, even though they have mental capacity. People with psychosocial disabilities might claim a lack of equality before the law, but as we shall see, legal equality is a contested concept.<sup>61</sup>

The MHA 1983<sup>62</sup> steers a careful line between protection of the individual's autonomy interests and protection of others. Amongst safeguards introduced in the Mental Health Act 2007 (which amends the 1983 Act), the definition of 'mental disorder' was revised<sup>63</sup> to limit the range of people who can be subjected to compulsory treatment under the Act, and section 3(4) of the 1983 Act now incorporates into the detention criteria a requirement that 'appropriate treatment is available' for

the opportunity to be heard in any judicial and administrative proceedings affecting the child ....' And see CRPD, Article 7(3): 'States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right.'

<sup>&</sup>lt;sup>55</sup> *R* (Axon) v Secretary of State for Health [2006] EWHC 37 (Admin).

<sup>&</sup>lt;sup>56</sup> *Re R* (n51); *Re W* (n33).

<sup>&</sup>lt;sup>57</sup> E. Cave, (n29).

<sup>&</sup>lt;sup>58</sup> S. Wildeman, 'Protecting Rights and Building Capacities: Challenges to Global Mental Health Policy in Light of the Convention on the Rights of Persons with Disabilities' (2013) 41(1) *The Journal of Law, Medicine & Ethics* 48.

<sup>&</sup>lt;sup>59</sup> B. Hale, 'Justice and Equality in Mental Health Law: The European Experience' (2007) 30(1) *International Journal of Law and Psychiatry* 18; L.O. Gostin, 'Human Rights of Persons with Mental Disabilities. The European Convention of Human Rights' (2000) 23(2) *International Journal of Law and Psychiatry* 125.

<sup>&</sup>lt;sup>60</sup> P. Bartlett, 'A Matter of Necessity? Enforced Treatment under the Mental Health Act' (2007) 15(1) *Medical Law Review* 86.

<sup>&</sup>lt;sup>61</sup> A. Kampf, 'Coercive Care: The Role of the Law in Treatment Decisions' in B. Mcsherry, I. Freckelton (eds) *Coercive Care: Rights, Law and Policy* (Routledge, 2013), 80.

<sup>&</sup>lt;sup>62</sup> As amended by the Mental Health Act 2007 and the Health and Social Care Act 2012.

<sup>&</sup>lt;sup>63</sup> Amending Mental Health Act 1983, s 1(2).

the patient concerned. A new section 58A requires that - except in an emergency - patients with capacity consent before electro-convulsive therapy (and certain other treatments) are administered.

Part 4 of the MHA, however, permits treatment without consent. And section 63,<sup>64</sup> which allows treatment of 'mental disorder' even where the patient makes a competent refusal, is not confined to cases where patients pose a risk to others.<sup>65</sup> Bartlett has argued that this 'throw[s] to the wind any concept of autonomy for the civilly or criminally confined psychiatric patient.<sup>66</sup> The United Nations Convention on the Rights of Persons with Disabilities (CRPD) and its Optional Protocol has brought about a paradigm shift in disability rights.<sup>67</sup> The Convention was adopted in 2006 and brought into force in 2008. The UK is one of 82 signatories. Though the Act is not directly enforceable in the UK courts, it has interpretive influence. The Convention protects equality and non-discrimination (Article 5), liberty and security of persons (Article 14) and dignity (freedom from inhuman and degrading treatment) (Article 15). Article 12 promotes the right of persons with disabilities to 'enjoy legal capacity on an equal basis with others in all aspects of life<sup>68</sup> and to appropriate measures of support in exercising legal capacity<sup>69</sup> in line with their 'will and preferences'.<sup>70</sup> Traditionally, mental health was viewed as an isolated issue requiring a tailored response. The Convention, however, explicitly incorporates mental disabilities within its remit.<sup>71</sup> There is a drive to separate the concept from purely medical terms and recognise the psychological and social interactions inherent in the term. Many now refer to 'psychosocial disability' rather than 'mental disorder'. As a result, basing differential freedoms and rights on the distinction between physical and mental disorder is becoming increasingly problematic. At the heart of the problem is the fact that the CRPD adopts a social model of disability that contrasts with the medical model inherent in MHA. The current regime has potential to breach rights to equality both by discriminating against those with cognitive impairment and by excluding from the remit of the Mental Capacity Act (and subjecting their decisions to override), groups who are considered vulnerable.

In summary, the previous two sub-sections have shown that there are gaps in the framework on capacity and human rights arguments challenging their acceptability. Another criticism of pre-MCA law by the 1995 Law Commission was that 'it does not rest on clear or modern foundations of principle' and 'has failed to keep up with social and demographic change'. It is to this we now turn.

<sup>&</sup>lt;sup>64</sup> Mental Health Act 1983, s 63: 'Treatment not requiring consent: The consent of a patient shall not be required for any medical treatment given to him for the mental disorder from which he is suffering, not being a form of treatment to which section 57, 58 or 58A above applies, if the treatment is given by or under the direction of the approved clinician in charge of the treatment.'

<sup>&</sup>lt;sup>65</sup> M. Kinson, *Coercion and Consent: Monitoring the Mental Health Act 2007-2009,* (The Mental Health Act Commission Thirteenth Biennial Report 2007-2009) (London, 2009).

<sup>&</sup>lt;sup>66</sup> P. Bartlett 'Psychiatric Treatment in the Absence of the Law' (2006) 13 *Medical Law Review* 124.

<sup>&</sup>lt;sup>67</sup> T. Minkowitz, 'The United Nations Convention on the Rights of Persons with Disabilities and the Right to be Free from non-Consensual Psychiatric Interventions' (2007) 34(2) *Syracuse Journal of International Law and Commerce* 405; P. Bartlett, 'The United Nations Convention on the Rights of Persons with Disabilities and the Future of Mental Health Law' (2009) 8(12) *Psychiatry* 496.

<sup>&</sup>lt;sup>68</sup> Article 12(2).

<sup>&</sup>lt;sup>69</sup> Article 12(3).

<sup>&</sup>lt;sup>70</sup> Article 12(4).

<sup>&</sup>lt;sup>71</sup> CRPD, Article 1: 'Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.'

C. <u>The law does not rest on clear or modern foundations of principle and has failed to keep up</u> with social and demographic change

Since the MCA came into force, 'modern foundations of principle' have indeed developed. The previous sub-section postulated that the legal framework may not adequately protect the individual autonomy rights of those excluded from the remit of the MCA. This section recounts recent criticism of the individual autonomy approach and argues that, in light of contemporary philosophical developments it is becoming increasingly important to deliver upon the concessions in the Act to a relational account.

# Relational Autonomy

The focus of the MCA is on those who lack capacity, but its empowering ethos, assumption of capacity and its restricted application of the best interests test to those who, on the balance of probabilities lack capacity, also provide important safeguards for those *with* capacity. Individual autonomy interests dominate insofar as the decisions of adults recognised as having capacity under the Act will generally prevail even where decisions are unwise, irrational and will lead to significant harm or death.<sup>72</sup> The Act adopts a procedural notion of individual autonomy, separating the process of making the decision from the content of the decision. This has potential to generate unwillingness amongst doctors to challenge capax decisions that are irrational, ill-thought out and will lead to considerable harm, which is problematic to rational choice theorists.

It is also at odds with the increasing prominence of relational accounts in contemporary philosophical debate which recognise that the procedural test, which focuses on individual decisionmaking, defies the clinical reality that most patients make decisions in conjunction with their doctors and families. Also, the emphasis on individual autonomy results in a preoccupation with the outcome of the decision. Critiques of individual autonomy and of consent as a mechanism of achieving and protecting it, <sup>73</sup> shift the focus to a consideration of the process by which the decision is made. A decision that is ultimately overruled, may have involved every effort to improve the patient's understanding and aid communication. It might have involved consultation with family members and efforts to persuade the patient to accept a course of action which is commensurate with optimum health. Or it may have involved none of these things. Viewed in isolation, the acceptance or rejection of a patient's decision is of limited significance. The Act's focus on individual autonomy can lead to a simplistic binary interpretation of capacity, which removes the incentive for discussion and thus for empowerment: <sup>74</sup> If a person makes what doctors consider an unwise refusal of treatment, capacity is assessed to determine whether or not that decision can be overridden in the patient's best interests. A finding of capacity renders the decision unassailable. It is not the job of the doctor to question it. A finding of incapacity, on the other hand, renders the decision subject to veto. The decision of another person is substituted for the decision of the patient.

 <sup>&</sup>lt;sup>72</sup> Airedale NHS Trust v Bland [1993] 1 All ER 821; Re T (Adult: Refusal of Treatment) [1992] EWCA Civ 18.
<sup>73</sup> D. Beyleveld and R. Brownsword, Consent in the Law, (Oxford 2007); A. Maclean, Autonomy, Informed Consent and Medical Law (Cambridge, 2009); S. McLean, Autonomy, Consent and the Law (Oxford, 2009).

<sup>&</sup>lt;sup>74</sup> Mental Capacity Act 2005 Select Committee: Oral and Written Evidence – Volume 1 (A – K), p 341. http://www.parliament.uk/documents/lords-committees/mental-capacity-act/mental-capacity-act-2005-vol1.pdf

Individual autonomy has traditionally dominated medical law and this has had a profound effect on medical practice. As O'Neill has said: '...demands that medical professionals respect autonomy and rights have become a constant refrain'.<sup>75</sup> Hall has argued that this is the result of 'mainstream liberal culture [projecting the] crude figure of the autonomous man'.<sup>76</sup> The focus on individual autonomy has caused to be overlooked the engagement, facilitation, discourse, constrained options, and power differentials which influence the doctor-patient relationship and ultimately the decision of whether or not to have treatment. Criticism of the pre-eminence of individual autonomy in medical law in general and capacity in particular, is mounting. For example, Fineman<sup>77</sup> challenges the fixation in law on individual autonomy and argues that the State should be more responsive to vulnerability. Autonomy, Fineman argues, is a result rather than a naturally occurring phenomenon. The State should focus on non-authoritarian measures to empower vulnerable people, rather than delineating the autonomous and non-autonomous – a delineation that, she argues, is built on myths.

#### Concession to relational autonomy

The MCA does make concessions to protecting relational autonomy interests insofar as the Act recognises the 'social embeddedness' of some individuals' routes to capacity. The MCA provides that some people should be *helped* to make their own decisions: the Act incorporates a duty to take 'all practicable steps to help'<sup>78</sup> individuals achieve capacity. A broad understanding of relational autonomy (as recognition that an individual's ability to make decisions is connected to his or her relationships with others) is not the antithesis of individual autonomy, but can be utilised to ensure that those capable of exercising an individual autonomy right (the right to decide) are empowered to do so.

The MCA's concessions to a relational approach focus on enablement and the relevance of the person's past and present views when making a decision in their best interests, but they are poorly implemented. The legislation is not currently living up to its promises to protect and promote even this limited conception of relational autonomy. The dominance of individual autonomy in the law on informed consent emphasised and accentuated the potential within the MCA as framed to prioritise individual autonomy interests. In practice, this has resulted in a stark delineation between those with and without capacity and deprioritised efforts to help people achieve capacity. In recent times, the weakening of the hegemony of individual autonomy and increasing recognition of the importance of the relational autonomy approach has resulted in additional scrutiny of the promises in the Act to facilitate capacity, and the Act has been found wanting.

In relation to vulnerable groups who are, to various extents, denied the protections of the MCA, the incorporation of relational accounts of autonomy is highly variable. The requirement of 'enablement' may be poorly delivered by the MCA, but it does not necessarily apply at all beyond the remit of the Act. The Select Committee's faith in the MCA framework as a means of balancing safeguarding and empowerment may be misplaced. Limitations flow from the framing of the Act and

<sup>&</sup>lt;sup>75</sup> O. O'Neill, Autonomy and Trust in Bioethics, (Cambridge, 2002), 4.

<sup>&</sup>lt;sup>76</sup> M.I. Hall, (n10), 63.

<sup>&</sup>lt;sup>77</sup> M. Fineman, *The Autonomy Myth: A Theory of Dependency* (New Press, 2005); M. Fineman, A. Gear (eds) *Vulnerability; Reflections on a New Ethical Foundation for Law and Politics* (Ashgate, 2013).

<sup>&</sup>lt;sup>78</sup> Mental Capacity Act, s 1(3).

from its interaction in clinical practice with laws that prioritise safeguarding irrespective of the individual's potential to make a supported decision.

The aim in this sub-section has not been to adjudicate the debates between relational and individual accounts of autonomy, but to point out that 'modern foundations of principle' have developed since the MCA came into force and that these developments make it increasingly important to recognise in law and practice that the capacity for self-governance is socially embedded and that empowerment and facilitation play an increasingly prominent role in protecting autonomy rights.

# **II IMPLEMENTING THE MCA**

The Law Commission's 1995 report on Mental Incapacity recommended that legislation was needed to address a regime that was 'unsystematic and full of glaring gaps'; did not 'rest on clear or modern foundations of principle' and 'failed to keep up with social and demographic change'; and which has 'failed to keep up with developments in our understanding of the rights and needs of those with mental disability'.<sup>79</sup> The first section has recounted arguments that these criticisms remain valid in relation to the framework on capacity that applies to medical treatment decisions. Whilst there are strong public policy grounds for protecting some vulnerable people from their own harmful decisions, the failure to apply the principles of empowerment and facilitation central to the MCA and the denial of capacity on the basis of status leads to pressure for reform.

The dominance of individual autonomy and charitable paternalism is giving way to a more nuanced approach which incorporates a relational approach and protects equality rights. The MCA makes concessions to both, but dictatorial and authoritative decisions on the basis of an individual's 'vulnerability' and differential recognition of rights on the basis of status are increasingly problematic in light of the 'paradigm shift' in the CRPD from charitable and medical approaches to disability to a human rights based approach. Indeed, the European Court of Human Rights now recognises that people are vulnerable by virtue of the discrimination they suffer.<sup>80</sup> Consequently, the paradigm shift is relevant not only to those with a disability but also to other vulnerable groups. Furthermore, enforceability is enhanced by the increased recognition of equality rights in the European Court of Human Rights, 'allowing the Court to address different aspects of inequality in a more substantive manner'.<sup>81</sup>

The lack of consistency in the principles that lie behind capacity laws relevant to medical treatment decisions is likely to compound the difficulties acknowledged by the Select Committee in implementing the MCA. So far, the focus in this paper has been on the conceptual problems that flow from having a definition of capacity that is not applicable to certain groups on the basis of their status, and denies some people who are recognised as having legal capacity the right to refuse treatment. It is worth noting that this also leads to practical problems for patients, families and doctors. One such problem flows from the complexity of the various laws, which makes it difficult to

<sup>&</sup>lt;sup>79</sup> Law Commission (n27), para 1.1.

<sup>&</sup>lt;sup>80</sup> For example, *Alajos Kiss v Hungary*, App. No. 38832/06, Judgment of 20 May 2010, [42] recognising those with psychosocial disorders as a 'particularly vulnerable group in society, who have suffered considerable discrimination in the past.' Discussed in L. Peroni, A. Timmer, 'Vulnerable Groups: The Promise of an Emerging Concept in European Human Rights Convention law' 11(4) (2013) *International Journal of Constitutional Law* 1056, 1057.

<sup>&</sup>lt;sup>81</sup> L. Peroni, A. Timmer, ibid.

know and assert rights or to challenge decisions. Another is the incongruous and incoherent ways in which the various tests come together. A 15 year old with anorexia nervosa might, in the space of a year, have to satisfy two different tests to determine capacity and be subject to veto regardless of capacity if her doctor chooses to invoke the MHA rather than the MCA regime. It is not always clear which is the more appropriate. The Court of Protection (a special section of the Court created by the MCA) recently ruled that a patient suffering from anorexia nervosa lacked capacity and could be subjected to compulsory treatment in her best interests.<sup>82</sup> The treatment would be authorised under the MHA where different principles apply, potentially leading to conflicts between the two regimes.<sup>83</sup>

The fact that the MCA focuses on the protection of individual autonomy interests leaves the broader regime open to criticism on the basis of the unfair and unequal ways in which individual autonomy rights are protected. The MCA leaves a number of gaps, which are filled by other statutes and common law. Disability and children's rights campaigners have argued that the reach and application of the core principles of the Act should be reconsidered in light of human rights advances. Proper implementation of the MCA and our ability to respond to human rights developments are dependent upon a wider commitment to empowerment and enablement both when the Act applies and in relation to the various laws that govern capacity alongside the MCA.

# III. WAYS FORWARD

# A. The universal capacity model

One option is to radically reform the MCA. We have seen that the Act as currently framed imposes limitations on the extent to which autonomy as an achievement can be fully realised in practice. Furthermore, there is a strong argument that the MCA breaches the UN Convention on the Rights of Persons with Disabilities.<sup>84</sup> Arguably, the focus in the test for incapacity on cognitive ability leaves the decisions of some individuals susceptible to veto on the basis of their status. Accordingly, some would argue that the Act gives inadequate protection to individual autonomy rights.

The Government ratified the CRPD in the belief that the MCA was compatible. But the language of the CRPD is open textured and interpretation has tended to follow a bottom-up approach: those who are treated differently by virtue of their status interpret the Convention so as to strengthen their position. A previous section in this article briefly contemplated the potential for the law's distinction between people with physical disabilities and psychosocial disorders (who may be able to make a capax decision under the MCA yet nonetheless be overruled in order to safeguard them from harm) to breach Article 12(2)'s promise of capacity on an equal basis as part of the commitment to equal recognition before the law. Interpretation of the CRPD could lead to more radical change still, if it is accepted that the focus on *mental* capacity is fundamentally flawed.

<sup>&</sup>lt;sup>82</sup> Re E (Anorexia) [2012] EWHC 1639 (COP).

<sup>&</sup>lt;sup>83</sup> G. Richardson, 'Mental Capacity in the Shadow of Suicide: What Can the Law Do?' (2013) 9(1) *International Journal of Law in Context* 87.

<sup>&</sup>lt;sup>84</sup> See W. Martin, *Consensus Emerges in Consultation Roundtables: The MCA is Not Compliant with the CRPD: Mental Capacity Law Discussion Paper* (2014)

http://www.39essex.com/docs/newsletters/uncrpd\_mca\_compatibility\_discussion\_paper\_final\_5\_8\_14.pdf

Article 12 of the CRPD promises appropriate measures of support in exercising legal capacity<sup>85</sup> in line with the individual's 'will and preferences'.<sup>86</sup> In place of mental capacity with its diagnostic<sup>87</sup> and functional<sup>88</sup> tests, a universal model of capacity would recognise that all individuals retain capacity, regardless of disability. Decisions would be supported to various (sometimes considerable) degrees so that everyone retains the right to make decisions according to their will and preferences. This interpretation of the CRPD has led to reforms and reform proposals in a number of countries. By way of example, Ireland's Assisted Decision-Making (Capacity) Bill, published in July 2013,<sup>89</sup> does not rely on the best interests test, proposing instead a model based on will and preferences.

In April 2014, a General Comment on Article 12 of the CRPD was issued by the United Nations Committee on the Rights of Persons with Disabilities (the Committee), set up under Article 34 of the Convention.<sup>90</sup> The Committee is critical of laws that deny *legal* capacity (ie 'capacity to be a holder of rights and an actor under the law') on the basis of cognitive impairment:

[In some countries a] person's ... decision-making skills are taken as legitimate grounds for denying his or her legal capacity and lowering his or her status as a person before the law. Article 12 does not permit such discriminatory denial of legal capacity, but rather requires that support be provided in the exercise of legal capacity.<sup>91</sup>

The Committee supports a 'universal capacity' approach. The Comment on Article 12 does not refer specifically to the Mental Capacity Act, but it is clear that it considers the MCA and similar regimes to breach Article 12. The MCA falls foul of the Committee's interpretation insofar as it recognises that some individuals lack mental capacity and that those who do are subject to the decisions of others. Radical reform of the MCA in light of the Committee's Comment would involve England and Wales abandoning both the best interests framework and the diagnostic threshold for incapacity.

# B. In defence of the MCA

The Mental Disability Advocacy Centre submitted evidence to the House of Lords Select Committee that the 'substituted decision-making regime' is contrary to Article 12 of the CRPD;<sup>92</sup> an issue that the Select Committee avoided on the basis that the compliance question was being considered by the judiciary in England and Wales.<sup>93</sup> The Government's response to the Select Committee report, Valuing Every Voice, Respecting Every Right, outlines commitment to the CRPD,<sup>94</sup> but it refers neither to the UN Committee Comment nor the potential for the MCA to conflict with Article 12. Neither is entirely surprising. The Government is not necessarily bound by the Committee's

<sup>&</sup>lt;sup>85</sup> Article 12(3). <sup>86</sup> Article 12(4).

<sup>&</sup>lt;sup>87</sup> Mental Capacity Act 2005, s 2(1).

<sup>&</sup>lt;sup>88</sup> Mental Capacity Act 2005, s 3(1).

<sup>&</sup>lt;sup>89</sup> Accessible at http://www.oireachtas.ie/documents/bills28/bills/2013/8313/b8313d.pdf.

<sup>&</sup>lt;sup>90</sup> Committee on the Rights of Persons with Disabilities, *General Comment No 1: Article 12: Equal Recognition* before the Law, CRPD/C/GC/1 (2014).

<sup>&</sup>lt;sup>91</sup> Ibid, para 13.

<sup>&</sup>lt;sup>92</sup> Select Committee (n7), para 83.

<sup>&</sup>lt;sup>93</sup> The Select Committee on the Mental Capacity Act 2005 *Inquiry on The Mental Capacity Act 2005*, Evidence Session No.1, 18 June 2013.

<sup>&</sup>lt;sup>94</sup> Valuing Every Voice (n25), 10.25.

interpretation and might well disagree with it.<sup>95</sup> That is not to say that the UN Committee's Comment has been swept under the carpet: Senior Judge Lush in the Court of Protection recently cited it in a case on undue influence,<sup>96</sup> and an independent review of the MCA's compliance with the CRPD by the Essex Autonomy Project considered the impact of the Comment when coming to a broad consensus (explored below) that the basic architecture of the MCA was compliant but that some reform is required.<sup>97</sup>

The second part of the title of the government's response to the Select Committee 'Making the Case for the Mental Capacity Act' makes the political position clear: the MCA is here to stay. In the UK's first compliance report on the CRPD published in 2011<sup>98</sup> it is opined that compliance with Article 12 is achieved through application of the Mental Capacity Act 2005. If the Government maintains this position, then one option before it is to diverge from the Committee's interpretation of Article 12, whilst remaining committed to the CRPD.<sup>99</sup> Compliance with the Convention requirement to respect the individual's rights, will and preferences might arguably flow from the assertion in section 4(6) of the MCA that the decision-maker must 'consider, so far as is reasonably ascertainable, the person's past and present wishes and feelings ... [and] the beliefs and values that would be likely to influence his decision if he had capacity'. Safeguards against 'unequal recognition before the law' rest on the focus in the MCA<sup>100</sup> on the assumption of capacity; the decision-specific focus of the test for incapacity; and recognition in section 2(3) of the MCA that:

A lack of capacity cannot be established merely by reference to-

(a) a person's age or appearance, or

(b) a condition of his, or an aspect of his behaviour, which might lead others to make unjustified assumptions about his capacity.

The adoption in the MCA of a functional test for incapacity may be more difficult to square with the CRPD. Under the MCA, those who lack *mental* capacity also lack *legal* capacity to make the relevant decision and this may conflict with the universal capacity model upheld in the Convention. However, the implications of the denial of legal capacity vary greatly from one jurisdiction to another. The Committee argue that:

[T]here are no circumstances permissible under international human rights law in which a person may be deprived of the right to recognition as a person before the law, or in which this right may be limited.<sup>101</sup>

<sup>&</sup>lt;sup>95</sup> The Select Committee Report (n7) states that the Government is conducting its own assessment of the matter.

<sup>&</sup>lt;sup>96</sup> London Borough of Haringey v CM [2014] EWCOP B23, [32].

<sup>&</sup>lt;sup>97</sup> See W. Martin, (n84); W. Martin, S. Michalowski, T. Jutten, M. Burch, Essex Autonomy Project, Achieving CRPD Compliance: Is the Mental Capacity Act of England and Wales Compatible with the UN Convention on the Rights of Persons with Disabilities? If Not, What Next? (2014). Accessible at http://autonomy.essex.ac.uk/uncrpd-report.

<sup>&</sup>lt;sup>98</sup> UK Initial Report on *The UN Convention on the Rights of Persons with Disabilities* (2011).

<sup>&</sup>lt;sup>99</sup> Ibid, para 6.

<sup>&</sup>lt;sup>100</sup> Though not necessarily beyond the remit of the Act (as argued above).

<sup>&</sup>lt;sup>101</sup> General Comment (n94), para 5.

In England and Wales, a lack of mental capacity may lead to the patient being denied the right to make *the decision* in question. It does not strip the individual of 'recognition as a person before the law'. The retention of civil rights when a person loses capacity to make a particular decision might be said to render any breach of Article 8 of the ECHR proportionate in light of the harmful consequences of non-treatment. Contrast this position with regimes where guardianship laws remove a *person's* legal capacity. On the basis of a person's status – perhaps a diagnosis of a psychosocial disability - they are stripped of their fundamental rights as persons.<sup>102</sup> In some countries people with certain psychosocial disabilities can be committed to an institution on the whim of a relative and their civil rights- their right to marry, vote or found a family – removed.<sup>103</sup> Substituted judgment – a judgment made by one person (or court) on behalf of another – can take a variety of forms.

In England and Wales, the MCA attempts to give effect to the views of the patient in a number of ways, including giving force to advance directives<sup>104</sup> and allowing the individual to nominate a proxy.<sup>105</sup> The powers of the proxy decision-maker are limited to decisions that are in the best interests of the person, taking into consideration their past and present views.<sup>106</sup> Abandoning this framework in favour of a supported-decision regime carries risks of its own. One is that it might fall perilously close to the same level of substituted decision-making, but under a different name.<sup>107</sup> Those patients who cannot communicate their decision require such a degree of 'support' as to render dubious any real reliance on their will and preference.

In conclusion, if the opinion of the UN Committee is accepted, then the MCA breaches Article 12 and major legislative reform will follow. If the government decides instead to adopt a contrasting interpretation of Article 12, I have outlined the basic factors that would be put forward in support of the argument that the MCA is compatible with the CRPD. Scrutiny of the UK's compliance with the Convention by the UN Committee on the Rights of Persons with Disabilities in 2015 will no doubt engage with this issue. It is abundantly clear from the 2014 House of Lords Select Committee report referred to in the earlier sections of this article, that even if the MCA can be said to comply with the CRPD in theory, it does not currently do so in *practice*. The failure to implement the facilitative ethos of the MCA, and the poor articulation in the Act and Code of Practice of the requirement to support decision-making<sup>108</sup> are out of line with the Convention. Any justification of the current form of legislation is dependent on the proper implementation of the MCA.

An alternative is to retain the MCA framework but subject it to reform. The Essex Autonomy Project on 'Achieving UNCRPD Compliance'<sup>109</sup> has come to the conclusion that the Committee is not correct in its assertion that compliance with the CRPD is dependent upon the abolition of substitute decision-making under the best interests framework. However it recommends that the words

<sup>&</sup>lt;sup>102</sup> Ibid, para 8.

<sup>&</sup>lt;sup>103</sup> Commissioner for Human Rights, *Who Gets to Decide? Rights to Legal Capacity for Persons with Intellectual and Psychosocial Disabilities* (Strasbourg, 2012).

<sup>&</sup>lt;sup>104</sup> Mental Capacity Act 2005, ss 24-26.

<sup>&</sup>lt;sup>105</sup> Mental Capacity Act 2005, ss 9-14.

<sup>&</sup>lt;sup>106</sup> Mental Capacity Act 2005, s 4(6).

<sup>&</sup>lt;sup>107</sup> G. Richardson, 'Mental Disabilities and the Law: From Substitute to Supported Decision-Making?' (2012) *Current Legal Problems* 333, 349.

<sup>&</sup>lt;sup>108</sup> See W. Martin (n84), para 22.

<sup>&</sup>lt;sup>109</sup> Essex Autonomy Project (n97).

'because of an impairment of, or a disturbance in the functioning of, the mind or brain' are removed from the section 2(1) test for incapacity on the ground that they are discriminatory and in breach of Article 5 of the CRPD; and that best interest framework breaches Article 12(4) of the CRPD and should be amended to incorporate a rebuttable presumption that a decision should be made in accordance with the wishes of the person lacking capacity. <sup>110</sup> This option is attractive but whilst it may resolve to the satisfaction of the Government the issue of MCA compatibility, compliance of the MHA with the CRPD would remain questionable.

# C. Legislating to harmonise approaches

The MCA is one of a number of laws that govern capacity to consent to and refuse medical treatment. When the MCA was enacted, the exclusion of young people and those with psychosocial disabilities was seen as justifiable on the basis that the groups are vulnerable and in need of charitable paternalism. We have seen that legal and human rights developments make this position increasingly difficult to defend. One option is to retain the current focus of the MCA on mental capacity and to retain the best interests framework, but to redesign the suite of laws that govern capacity to consent to medical treatment in order to bring about a consistent regime, so responding to the criticism that the current regime renders some groups unequal before the law in breach of Article 12 of the CRPD. The idea would be to introduce a fused approach to capacity.

Morrissey has argued that the incorporation of mental health within the CRPD will result in a paradigm shift in terms of rights. The provisions of the CRPD, and in particular, the requirement in Article 12 that people with disabilities are supported in their exercise of legal capacity, will drive mental health reform.<sup>111</sup> The argument that two separate schemes for compulsory treatment - one for physical and the other for mental disorder - is unnecessary and discriminatory is growing in force. It is clear that 'mental disorder' does not, of itself, signify incapacity. In a 2000 study, capacity (as defined in the, then Mental Capacity Bill) was assessed in three different mental disability groups.<sup>112</sup> Whilst those with learning disabilities and dementia were significantly less likely than the general population to have capacity, the same could not be said of the group with mental disorders. This was especially so when care was taken to present information to the patient in an appropriate form.<sup>113</sup>

On the other hand, the MCA test for incapacity does not incorporate those non-autonomous decisions that flow from a lack of insight into a psychosocial condition. But this factor does not render those with psychosocial disabilities unfit for inclusion within a capacity-based model. A solution might be to alter the definition of capacity so that those, whose conditions affect their insight, are not viewed as having the requisite capacity. The test would apply to all, as would the empowering and enabling ethos of the Act. A number of countries seek to do just that. For example, in Australia, Bills in Victoria and Tasmania propose to allow coercive treatment for mental disorder

<sup>&</sup>lt;sup>110</sup> Accessible at http://autonomy.essex.ac.uk/uncrpd-report.

<sup>&</sup>lt;sup>111</sup> F. Morrissey, 'The United Nations Convention on the Rights of Persons with Disabilities: A New Approach to Decision-Making in Mental Health Law' (2012) 19 *European Journal of Health Law* 423.

<sup>&</sup>lt;sup>112</sup> J.G. Wong, et al, 'The Capacity of People with a 'Mental Disability' to Make a Health Care Decision' (2000) 30 *Psychological Medicine* 295.

<sup>&</sup>lt;sup>113</sup> And see the famous MacArthur study discussed in T. Grisso, P. Applebaum, 'The MacArthur Treatment Competency Study III: Abilities of Patients to Consent to Psychiatric and Medical Treatment' 19(2) (1995) *Law and Human Behavior* 149.

only where the patient lacks legal capacity.<sup>114</sup> Szmukler, Daw, and Dawson have outlined a draft fused law on capacity and mental health which might be applied in England and Wales.<sup>115</sup> The proposal is for a unified scheme for incapacity, whether it is caused by learning disability, depression or head injury.<sup>116</sup>

Fused models incorporating young people are altogether rarer. This reflects the primacy of the best interests principle<sup>117</sup> in decisions about minors and wide disagreement as to how best to protect best interests when young people refuse life-sustaining treatment. The 'evolving capacities' approach of the UN Convention on the Rights of the Child can arguably be accommodated within a future-orientated view of autonomy<sup>118</sup> in which case refusals of treatment might be overruled to protect minors' 'best-desire' or 'ideal-desire'<sup>119</sup> autonomy, rather than their current desire. I have argued elsewhere that a sufficiently robust capacity test would protect best interests,<sup>120</sup> in which case young peoples' capax decisions should be upheld in the same way as adults'. As we have seen, behind the paradigm shift inherent in the CRPD, lies a rejection of charitable paternalism and a new focus on enablement. Calling upon the same principles to uphold children's autonomy rights, could to lead to comparable advances.

There are examples of fused capacity laws that apply to adults and young people. In Ontario, Canada, the Health Care Consent Act 1996 operates a presumption of capacity that applies irrespective of age and that is accompanied by a duty to facilitate capacity.<sup>121</sup> A guide has been developed to help doctors apply the test to minors.<sup>122</sup> The model is progressive, but some commentators fear that a test which fuses adult and child capacity is necessarily broad and can therefore leave some *adult* groups susceptible to a finding of incapacity if the outcome of their decision is considered undesirable.<sup>123</sup> In other words, a more inclusive test may result in a more malleable test which is less protective of individual autonomy.

Perhaps this consideration was relevant to the rejection in Northern Ireland of the Bamford Review proposal to fuse adult and child capacity tests.<sup>124</sup> The Review identified the need to move away from a status-based test and to recognise the evolving capacities of children. It suggested that a

<sup>&</sup>lt;sup>114</sup> S. Callaghan, 'Rising to the Human Rights Challenge in Compulsory Treatment-New Approaches to Mental Health Law in Australia' (2012) 46(7) *The Australian and New Zealand Journal of Psychiatry* 611.

<sup>&</sup>lt;sup>115</sup> G. Szmukler, R. Daw, J. Dawson, 'A Model Fusing Incapacity and Mental Health Legislation' (2010) April *Journal of Mental Health* 11.

<sup>&</sup>lt;sup>116</sup> Ibid.

<sup>&</sup>lt;sup>117</sup> UNCRC, Article 3.

<sup>&</sup>lt;sup>118</sup> J. Eekelaar, 'The Interests of the Child and the Child's Wishes: The Role of Dynamic Self-Determinism. (1994) 8 *International Journal of Law and the Family* 42.

<sup>&</sup>lt;sup>119</sup> J. Coggon, 'Varied and Principled Understandings of Autonomy in English law: Justifiable Inconsistency or Blinkered Moralism?' (2007) 15 *Health Care Analysis*, 235.

<sup>&</sup>lt;sup>120</sup> E. Cave, (n 29).

<sup>&</sup>lt;sup>121</sup> Health Care Consent Act 1996, s. 4(1).

<sup>&</sup>lt;sup>122</sup> R. Geist and S.E. Opler, 'A Guide for Health Care Practitioners in the Assessment of Young People's Capacity to Consent to Treatment' (2010) 49(9) *Clinical Pediatrics* 834.

<sup>&</sup>lt;sup>123</sup> A. Carling-Rowland and J. Wahl, 'The Evaluation of Capacity to Make Admission Decisions: Is it a Fair Process for Individuals with Communication Barriers?' (2010) 10(3) *Medical Law International* 171.

<sup>&</sup>lt;sup>124</sup> The Bamford Review of Mental Health and Learning Disability (Northern Ireland), A Comprehensive Legislative Framework: Consultation Report (Belfast, 2007),

rebuttable presumption of capacity might be applied from age 12-16.<sup>125</sup> The capacity test and protections would be applied to everyone aged 12 and over, but the rebuttable nature of the test would protect the welfare interests of those who lack capacity.

This section has argued that reform of the MCA to improve compliance with the CRPD would not be a panacea. A broader scheme of reform, whilst attractive in principle, is hugely complex in practice. In light of this it is perhaps unsurprising that, whilst some states are bravely tackling these issues in relation to minors or those with psychosocial disabilities, none have yet proposed a scheme which encompasses them both.

# D. Fusion by stealth

If, as seems likely in the political climate, the broad scheme of the MCA is retained (in preference to a new, universal capacity model or a new fused legislative model), compliance with human rights will depend on a more gradual means of bringing the various laws into line. In the UK, an empowering ethos is making its way into other legislation. The Equality Act 2010 definition of disability incorporates both physical and mental impairment.<sup>126</sup> And Article 12 of the CRPD has influenced new protections for people with disabilities in the Care Act 2014, not least in the establishment of the right to an independent advocate.<sup>127</sup> There are also signs of changes in clinical practice. For example, a spate of cases in the 1990s resulted in non-consensual treatment of minors who withheld their consent to life-sustaining treatment. There has been few<sup>128</sup> such case since 2003, ostensibly due to discomfort with the authoritarian measures it necessitates. There is a preference for persuasion and where that fails, a recognition that non-treatment may be in the interests of the minor.<sup>129</sup> The General Medical Council now endorses a partnership model between doctor and patient.<sup>130</sup>

In case law too, there is evidence of an effort to move the focus from mental capacity as an expression of autonomy to capacity as an achievement of autonomy. The case of DL v A Local Authority & Others, <sup>131</sup> though controversial, <sup>132</sup> does incorporate an attempt to move away from a dictatorial approach to a more facilitative position. In DL, the Court of Appeal sought to fill a gap left by the Mental Capacity Act in a manner commensurate with the principles of the Act. The couple in question had capacity according to the test set down in the MCA, but were subject to undue influence from their son. The Court ordered that they should be given the opportunity to make a

<sup>&</sup>lt;sup>125</sup> Ibid, 5.45: 'The implications of a capacity approach to all substitute decision-making legislation would require the same basic approach to be applied for children. While most people would agree that parents be substitute decision-makers for children up to the age of 10 or 12, consideration might be given to a rebuttable presumption of capacity between 12 and 16. ...'  $^{126}$  Equality Act 2010, s 6(1)(a).

<sup>&</sup>lt;sup>127</sup> See discussion in Lucy Series' Blog *The Small Places* (an excellent resource of commentary and materials on mental capacity and the CRPD): accessible at https://thesmallplaces.wordpress.com/2014/06/06/hiddengems/

<sup>&</sup>lt;sup>128</sup> An urgent out of hours application to treat a 17 year old girl following a drug overdose was granted in An NHS Foundation Hospital v P [2014] EWHC 165. 'P' withheld consent and did not lack capacity. Discussed in S. Pattinson, Medical Law and Ethics (Sweet & Maxwell, 4th ed, 2014), 5–029.

<sup>&</sup>lt;sup>129</sup> E. Cave, Nuffield Foundation Report: Young People who Refuse Life Sustaining Treatment: A Briefing Paper on Current Law and the Need for Reform (April 2013), accessible at

http://www.nuffieldfoundation.org/adolescents-and-informed-consent.

<sup>&</sup>lt;sup>130</sup> General Medical Council, *Good Medical Practice* (Manchester, 2013), paras 46-52.

<sup>&</sup>lt;sup>131</sup> [2012] EWCA Civ 25.

<sup>&</sup>lt;sup>132</sup> See n31 above.

free and unencumbered decision. McFarlane LJ agreed with the decision of *Re SA (Vulnerable Adult with Capacity: Marriage)* where it was held the inherent jurisdiction is '... aimed at enhancing or liberating the autonomy of a vulnerable adult whose autonomy has been compromised by a reason other than mental incapacity.'<sup>133</sup> The judges did not substitute the couple's decisions with a court-imposed welfare decision, but commended a facilitative approach,<sup>134</sup> which is 'entirely on all fours with the re-establishment of the individual's autonomy of decision-making in a manner which enhances, rather than breaches, their ECHR Article 8 rights'.<sup>135</sup>

A similar approach can be discerned in *Aintree University Hospital Foundation Trust v James*,<sup>136</sup> in which the Supreme Court emphasised the importance of considering best interests from the perspective of the patient. Also, a recent decision in the Court of Protection in *Westminster City Council v Sykes*<sup>137</sup> focused on Ms. Manuela Sykes' will and preferences, wishes and beliefs in coming to the decision that she be allowed to return home. And in *Re S and S (Protected Persons)*,<sup>138</sup> Judge Marshall said that the MCA 'effectively gives rise to a presumption in favour of implementing [the individual's] wishes, unless there is some potential sufficiently detrimental effect for P of doing so which outweighs this.'<sup>139</sup> This view is controversial,<sup>140</sup> but it signifies an attempt to strengthen judicial commitment to the will and preference of those lacking capacity.

A new age of supported decision-making is upon us, and our ability to implement and extend the empowering ethos of the MCA depends not only on a better understanding of the MCA but on a willingness to adapt the suite of laws and guidance pertaining to medical treatment decisions.

# CONCLUSION

The MCA has recently come under intense criticism. The House of Lords Select Committee report indicates that seven years after the Act came into force it remains poorly understood and implemented. The protections of rights on 'paper' are not followed through in practice. The Government has acknowledged the failure to properly implement the MCA. It will 'consider the case' for establishing an independent Mental Capacity Advisory Board to raise awareness and advise the Government;<sup>141</sup> host a national event to raise awareness;<sup>142</sup> and the Department of Health will commission a review of its guidance.<sup>143</sup> The Government remains firmly committed to the MCA:

<sup>&</sup>lt;sup>133</sup> [2005] EWHC 2942 (Fam), [54].

<sup>&</sup>lt;sup>134</sup> [2012] EWCA Civ 25, [67].

<sup>&</sup>lt;sup>135</sup> Ibid.

<sup>&</sup>lt;sup>136</sup> [2013] UKSC 67.

<sup>&</sup>lt;sup>137</sup> [2014] EWHC B9 (COP).

<sup>&</sup>lt;sup>138</sup> Re S and S (Protected Persons); C v V [2008] EWHC B16 (Fam).

<sup>&</sup>lt;sup>139</sup> Ibid, [57]. And at [56]: 'The Act does not, of course, say that Ps' wishes are to be paramount, nor does it lay down any express presumption in favour of implementing them if they can be ascertained. Indeed the paramount objective is that of P's "best interests". However, by giving such prominence to the above matters, the Act does, in my judgment recognise that having his views and wishes taken into account and respected is a very significant aspect of P's best interests. Due regard should therefore be paid to this recognition when doing the weighing exercise of determining what is in P's best interests in all the relevant circumstances, including those wishes.'

<sup>&</sup>lt;sup>140</sup> W. Martin (n84), para 19.

<sup>&</sup>lt;sup>141</sup> Valuing Every Voice, (n25), para 2.3.

<sup>&</sup>lt;sup>142</sup> Ibid, para 2.4.

<sup>&</sup>lt;sup>143</sup> Ibid.

The Government believes the MCA is an Act of fundamental importance which we are committed to embedding across our work programmes.<sup>144</sup>

It sees the MCA as the mechanism by which to 'value every voice' and respect 'every right of those who may lack capacity'.<sup>145</sup> This article has argued that this approach is flawed. First, the dominance of individual autonomy renders the MCA limited in its ability to empower individuals. Second, in relation to decisions to consent to and refuse medical treatment, the MCA is but one of a number of relevant laws. An individual's decision can be overruled despite being considered capax under the Act. Where this is to protect the patient (rather than others) from harm and flows from recognition of the person's vulnerability, there is potential for this to breach Article 12(2) of the CRPD which states that 'States Parties shall recognise that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life'. An emerging body of case law in the European Court of Human Rights has focused on States' tests for capacity.<sup>146</sup> Where the test is based on discriminatory and out-dated notions that vulnerable people should be subjected to charitable paternalism, there is potential for legal challenge. In England and Wales it is also the case that an individual can be required to satisfy a different, more stringent test for capacity in which case empowerment and facilitation may not be required by law. This is problematic because healthcare professionals are then expected to value safeguarding and empowerment to different degrees, depending on the status of the patient.

Implementation of the MCA and compliance with human rights developments require that we consider the Act in context. In this article I have focused on the right to consent to and refuse medical treatment in order to demonstrate the variable and incoherent ways in which capacity is recognised and acted upon. The focus on the Act in isolation ignores the reality that healthcare professionals and patients must function in a system where there are in fact a number of different *tests* for capacity and *implications* flowing from a recognition that a decision is capax. The facilitative approach engendered in the MCA is a commendable goal, but its effectiveness is limited by the overarching scheme of legal capacity to consent to medical treatment, parts of which are based on out-dated notions of paternalism which focus on status as opposed to capability to make an autonomous decision. Even if the proposals for MCA reform put forward by the Essex Autonomy Project are accepted, the potential for mental health law to breach the CRPD and for laws relating to child consent to conflict with the CRC remains. This is both inherently problematic and a practical barrier to implementation of the MCA.

<sup>&</sup>lt;sup>144</sup> Ibid, para 2.8.

<sup>&</sup>lt;sup>145</sup> Ibid, para 2.9.

 <sup>&</sup>lt;sup>146</sup> Shtukaturov v Russia (Application no. 44009/05), Judgment of 27 March 2008; Berkova v Slovakia, (Application no. 67149/01), Judgment of 24 March 2009; Salontaji-Drobnajak v Serbia (Application no. 26500/05), Judgment of 13 October 2009; Lashin v Russia, (Application no. 33117/02), (2013) E.C.H.R. 63; M.S. v Croatia (Application no. 36337/10), Judgment of 25 Apr 2013.